Computer-Based Patient Record: The Essential Data Set Approach

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Abstract

The clamor for data to study the impact of care, to evaluate clinical performance and justify resource utilization is increasing. The data in demand normally should exist in the record of a clinical encounter. Advances in information technology and software techniques have provided us with tools to develop and implement computer-based patient record systems. The issues that constrain development are integral issues of clinical medicine, such as the variability in medical data, specialized practice of medicine, and differing demands of the numerous end-users of a medical record. This paper describes an approach to develop a computer-based patient record. The focus is on identification of the essential data set by infological data modeling and its implementation in a commercially available package for a physician's office.

INTRODUCTION

The paradigm shift in health care management from monitoring the "process of care" to evaluating the "outcome of care" is driven by economic forces[1]. The foundation of all scientific decisions is information. Inadequate information places a decision maker, who may be: a physician, a nurse, an administrator or a clinical epidemiologist, in a dilemma. In the normal course of events much of the desired information would be in a clinical encounter record.

Paper based patient records have natural limitations, such as legibility, access and availability round the clock.

In a medical record due to lack of structure there is either excessive detail or a paucity of clinically relevant data. Computer adds value of automation to information and a computer-based medical record would provide care providers timely access to accurate data [2]. The panel on Computer based Patient Record (CPR) called by the Institute of Medicine has reviewed the need along with the current information technological advances. In conclusion explicitly state that technology is no longer a barrier [3].

At Norwalk, a practice based outcomes research study in chronic obstructive pulmonary disease has been initiated with application of Informatics tools and methods [4]. The emphasis was on developing a CPR to serve as a common tool for data collection from multiple sites. Later apply the structured approach perfected in Medical Informatics research to make explicit the knowledge that lies in our patient records from past clinical experience [5,6]. This feed-back to the care providers would result in clinical practice of high quality and introduce cost effectiveness in care.

The key challenges addressed in the Informatics approach were the issue of data taxonomy, coding, nomenclature, clinical classification using clinimateric indexes and developing a CPR to serve as a uniform data collection tool. In a recent review article Feinstein recommends such an approach to clinical research [7].

In this paper the approach to definition of data is outlined Then describe electronic implementation of the data set in a commercial application, the Medical Electronic Desktop [MED].

BACKGROUND

In computerization of patient records the earlier direction was to replicate the paper based patient record and techniques employed were to manage free text. In information systems that permit free text entry, either there is not adequate data to reconstruct the reason of clinical encounter [8]. Else, there is so much data that we drown in information as in the case at an academic center that led to abandonment of a CPR experiment [9].

Developers to make a CPR must address the three major problems:

- Structure, as in layout
- Semantics, as in issues of interpretation and coding
- Content, as the level of detail in data collected.

Weed, presented a revolutionary orientation for recording a clinical encounter in what he described as the "problem oriented medical record" [10]. As an

organizational format it was most appropriate for a quick review of the clinical encounter record. It provided the design stimulus for many patient record computerization projects. The issue of structure has more recently found attention from many quarters. The Sub-Committee ASTM E31.12 of the American Society for testing and materials circulated a draft report that outlines a generic structure and describes the architectural design of a CPR [11].

Medical data, as Prof. Blois emphasized, is the central issue for medical Informatics research [12], since that is the subject of medical computing [13]. The issue of semantics and management of the large terminology base has led to the development of coding schemes. The UMLS Meta-thesaurus project is designed to tackle the problem of the numerous coding schemes utilizing computer power [14]. The appropriateness of the various coding systems is under evaluation by a working group of the Computer-based Patient Record Institute.

The matter of content remains a neglected issue. Insufficient detail or lack of uniformity patient data makes it difficult to compare performance of different hospitals and there is an information gap [15]. Uniformity in content is desirable, specially to compare and evaluate effects of interventions [1, 16]. One needs to insure the content is adequate to reconstruct the clinical encounter [17]. In a multi-

utilization at the clinical encounter. An Essential Data Set for a clinical domain must include the data elements required to support clinical decision making, by all levels of care providers. Indirectly the same data elements should support administrators to monitor the resource utilization and researchers to evaluate the impact of the care provided. All data elements may not be required by all the care providers, at all sites or by the administration must be kept in mind. Duplicate elements may be eliminated, and some qualifications need to be made so that the set is definable.

A data element in an *Essential Data Set* for a clinical domain must fulfill some of the following criteria:

- easy to collect, preferably at the least cost
- provide information related to health status
- assist in risk and clinical assessment during encounters
- reflect the actions or interventions undertaken
- should assist in assessment of an outcome or have a predictive value for an outcome
- should reflect the actual outcomes.

Defining the EDS

Data modeling, a recognized technique used in systems development process was applied in identifying the EDS. In data modeling the objective

Figure 1 Decision Making Role Analysis of the Essential Data Set

	@ First encounter	dwing History	dwing Physical	dwing Follow-up	for summary	for research	Action Initiated
Nocturnal Cough Starts immediately							
after an hour							
>3 hours							
Stops when patient sits-up							
Does the patient complain of wheezing							
	1		1	1			

center research study, the essential data set approach was identified as one approach to develop health application software that could be used at multiple sites. The uniform data collection tool made it possible for experiences from the sites to be compared [18].

THE ESSENTIAL DATA SET APPROACH

An Essential Data Set (EDS) is the core data set that is essential to support decision making in a clinical setting. Elements in an EDS should be adequate to enable a clinician to describe the health status at the time of the encounter. In a retrospective mode enable evaluation of prior provider actions and resource

is to identify information requirements of application users. A group of pulmonary physicians was led by a trained medical Informatics specialist with prior experience in defining a data set.

The infological modeling approach as described by Sundgren [19] was adopted, first performing information analysis and then *normalization*. In an infological data model, data specification is in purely logical terms. An object can exist independent of any property or relationship pertaining to it. The first step was enumerating the data list from the soft situational perspective. The list was normalized and reduced from a functional perspective and finally a second normalization after an analysis of the data for

its traditional decision making use. See form used in Figure 1. An EDS was thus defined to record an encounter with a chronic obstructive pulmonary disease patient.

The essential data set was organized in a paper format of a standard medical record. This was used for data extraction during review of charts. Many data elements were added as the records required to support research need greater detail. To support outcomes research elements to assess functional capacity were included.

Electronic Implementation

pulmonary EDS.

The next step was to implement the pulmonary EDS in a software to provide the project with common data collection tool. The first option was to develop the entire software application package using commercially available application programs, as in a previous experience [20]. The other option was to use an available package for a physician's office and modify it to incorporate the

After an evaluation of available packages, Medical Electronic Desktop[©] a commercially available package developed by JAM Software of Australia, was selected. The package runs on Apple Macintosh computers with the simplest available configuration. The 'click and run' user *interface* of a Macintosh computer is

The package is stable and designed for use in the physician's office. It has four components:

easier with a shorter learning curve

appropriate for clinicians who are busy.

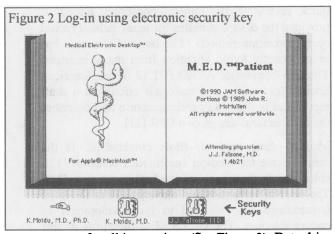
MED Patient - the patient record management component.

MED Maker - a utility tool-box to modify the MED Patient to modify the record system and the knowledge base.

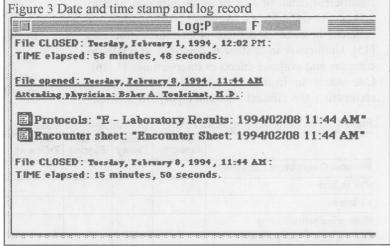
MED Extract - a tool to support extraction of data from the patient record to any statistical package for analysis of data.

MED Billing - To include practicing clinicians into the study the financial management aspect has to be kept in mind. The availability of such a component was considered important to gain acceptance for a common data collection tool.

The access to the system requires an electronic key, (See Figure 2) a log is maintained by a time date



stamp for all interactions (See Figure 3). Data driven support functions can be easily implemented using the tool box. The pulmonary EDS was incorporated along with the knowledge base in to the Medical Electronic Desktop using MEDmaker. The effort to incorporate was approximately 4 man-weeks of



effort. It allowed the project group to maintain a clinical focus while developing of the CPR - MED-Pulmonary.

DISCUSSION

In traditional research with a statistical design manual data collection and management, a small set of variables are collected. On the assumption that all change is reflected in that small set and all other data elements can be excluded. The use of computers has often been limited to data analyses.

In an Informatics approach the power and potential of the computer must be fully utilized. If there is to be a significant shift in the research paradigm towards an Informatics approach then the computer

must be introduced in data collection and management. This would enable us to collect greater detail, in essence collect all data variables that may influence a clinical situation under study. It would also permit us to collect data prospectively and analyze it retrospectively applying natural criteria to stratify the cohort. The data collection tool designed as an instrument to support the clinical care provider would improve the data quality, as the collector of data is also the first user of the data.

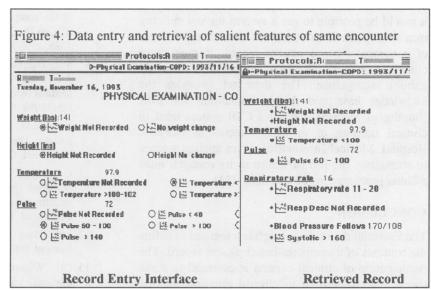
A critical step in the project was defining of the pulmonary EDS. It

was with an objective to collect detailed History and Physical examination findings in a clinical setting. It was extended, at this stage to assure thorough data collection. The pulmonary-EDS will be reduced in the future as the redundant data elements are removed, just as a clinician through years of practice adopts short cuts. The principle objective of the CPR in this case is to support in data collection in a physician's office for the outcomes research study.

The expansive data set comes with an overhead of time, it took almost an hour (See in Figure 3) and was a major hurdle to initiate the pulmonary fellows to use the system in the busy clinical settings. However, subsequent encounters required around 4-11 minutes for up-dating a record. The value of the

detailed first history was later appreciated by the clinical staff in the follow-up encounter, led one of them to state "I now really know more about the patient in a shorter time." The relevant details collected can be retrieved on review, making data reduction an automated process (See Figure 4).

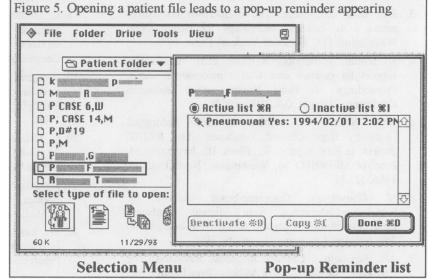
The ease with which one could set data driven reminders made the system acceptable to the clinical staff. The reminders list provided them with a powerful tool to provide team care, sharing plans for clinical work-up and follow-up. It also provided them with a list of reminders for communication with the patient, such as advice on smoking cessation,



vaccination, or a therapy. See figure 5. The pulmonary-MED system was used in the pulmonary clinics for recording all cases. The implementation strategy was the "agent of change" approach, where a member of the clinical team was trained with the intention he will provide a role model and train the fellows as they rotated through the clinic.

The pulmonary-MED system has security in terms of access limited by a digital key. There is also security in the detailed log maintained, that identifies the end-user and a summary of actions of the end-user. The system manager is able to define the access levels, but not make alterations in a record.

Availability of tools such as MED makes it possible to focus on the clinical issues in the development of



a computer-based patient record. Under the guidance

of a Medical Informatics expert and some assistance it would be possible to get a system up and running in a short time. Data content is the critical element of a computer-based patient record, it must have clinical relevance. The EDS approach is currently gaining acceptance. The data set provides the knowledge base and design foundation for IMR [Intelligent Medical Record] a CPR system used in clinical training of medical students at Norwalk Hospital. Medical Informatics, as an applied science to strengthen the infrastructure in its research must address problems 'inside medicine' [21].

CONCLUSION

The Essential data set approach is a method to define the contents of a computer-based patient record. The participation of clinical experts is essential to make the system responsive to clinical decision making needs. In the new systems architecture, with a client-server database; with the EDS defined for each clinical domain a hospital wide patient record system could be developed. The shared data elements would provide the foundation for horizontal logical integration.

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